

METUPOK ANNUAL REPORT

NOVEMBER 2021-APRIL
2023



“I am delighted that METUPUK has completed our first 16 months as a registered charity. Looking back, it is amazing to see how far our organisation has come since I first set it up in 2016.”

Jo Taylor, METUPUK Founder and Chair



The seeds of METUPUK were planted in 2015, when a group of women in the United States came together to campaign for better awareness and treatment options for metastatic breast cancer (MBC). Unfortunately, little has changed between then and now, and metastatic breast cancer still has poor outcomes because data is not collected and we are not counted when we are alive. Around 30% of people with breast cancer can expect to develop MBC, defined as when breast cancer spreads in the body beyond the breast and nearby lymph nodes. Some are diagnosed with de novo metastatic breast cancer, when spread is found at the same time as first diagnosis. For others, it can occur at any time, including up to 20 or 30 years after a primary diagnosis. We have no reliable UK data on MBC, but in the US, median life expectancy is between 2-5 years depending on sub-type, and at five years after diagnosis just 31%* of people are expected to be alive.

Since our beginnings in 2016 and our registration as a charity in 2021, METUPUK has grown as a patient advocacy organisation. Many amazing patients joined our cause and helped to formulate our strategy. Most of these women who supported us in the early days have now died, but the METUPUK of today stands on their shoulders. We had passionate fundraisers whose generosity and drive gave our charity an opening bank balance of £13,800 when we registered in November 2021. At the end of our first year as a charity, our closing balance was over £62,000. We are incredibly grateful to all our generous donors and hardworking fundraisers. In this report we shall outline how these funds have been used to further our charitable purposes.

*<https://seer.cancer.gov/statfacts/html/breast-subtypes.html>

The 16 month period which forms our first financial year has seen the Charity lose too many volunteers from metastatic breast cancer. Our board of Trustees has lost two members, and we are shaped by their influence and mourn the loss of them.



**LOUISE
FURNEAUX**

Trustee, Secretary
Died September 2022



**CONNIE
JOHNCOCK**

Trustee, Treasurer
Died March 2023

We rely on the work of our Trustees and also our patient advocate volunteers. None of us draw a salary from the Charity and METUPUK would not function without all the people who freely give their time and expertise. I thank everyone who has helped us become the organisation that we are today.

A 2-3 year median life expectancy for MBC is not a statistic to rejoice in but rather a demonstration of how much more needs to be done.

JO TAYLOR

Founder/Chair
METUPUK

"I am passionate about creating change for patients especially those with MBC. The only way change will happen is for us to demand change together as a group. We cannot continue with the same outcomes and with women dying at the same rate."

OUR PEOPLE



Trustees during financial period 9 November 2021- 5 April 2023 were Jo Taylor (Chair), Andy Figgins, Constance Johncock (Treasurer, died March 2023), Helen Steele, Julia Bradford, Louise Furneaux (Secretary, died September 2022) and Madeleine Meynell.



**JO
TAYLOR**

Founder/Chair
METUPUK



**ANDY
FIGGINS**

Trustee - Friends and
Family Support



**DR HELEN
STEELE**

Trustee - Research and
Clinical Trials



JULIA BRADFORD

Trustee -
Internal Operations



MADELEINE MEYNELL

Trustee -
Access to Drugs

Trustee Recruitment

Founding Trustees were recruited from volunteers of the METUPUK precursor organisation and worked together to create the Charity. Our constitution requires at least one trustee to have metastatic breast cancer. New Trustees are elected by the board of trustees where a skill shortage has been identified. We have a trustee with responsibility for the induction of new trustees, and each trustee is provided with a copy of The Essential Trustee.

"Without our dedicated and amazing volunteers we wouldn't have been able to achieve the breadth and reach of our work this year. They are at the heart of METUPUK"

Helen Steele, Volunteer Manager, Trustee



A proportion of our funds are spent on providing trustees and volunteers with the tools to be effective advocates. These include but are not limited to:

- Marketing information for events. i.e. printed documentation, roller banners, equipment, stand costs.
- Funding patient advocates' travel to attend meetings to represent METUPUK because volunteers are located across the UK.
- Funding IT/telephone costs for our website and secure Microsoft document storage.
- Providing email addresses to trustees and volunteers and access to SharePoint and Microsoft 365.

We do not have any paid staff but we do use external suppliers on an ad-hoc basis for website maintenance, campaigns and to produce a monthly newsletter.

OUR AIMS AND OBJECTIVES

Our Strategy in our first financial year is summarised across three main areas; **Awareness and Education, Research and Access to Drugs** and **Patient Treatment and Care**. These were formulated with the intention of providing benefit to the public and to patients with MBC.

AWARENESS AND EDUCATION

METUPOK Aims and Objectives:

MBC is currently incurable. We highlight the harsh reality of MBC which is not well reflected in the 'pink' celebratory campaigns. Alongside increasing public awareness, we challenge and educate policy makers, charities and government bodies to ensure that MBC is a priority for funding, research and innovation. We work to ensure that MBC is represented on all Trusts or Boards of breast cancer organisations, ideally by patient advocates being included as Trustees or Board Members. We work with Cancer Alliances and Health Boards to ensure primary breast cancer patients are provided with the tools and information to understand and recognise the symptoms of MBC. This encourages earlier MBC diagnosis and earlier treatment, thereby improving quality of life and survival prospects. During this financial year we have run two major awareness campaigns; **Darker Pink** and **True Crimes**.

DARKER PINK

The Darker Side of Pink' is a physical interactive experience which highlights the seriousness of Metastatic Breast Cancer - the biggest killer of women aged 35-64



with cancer in the UK. The impactful exhibition features 31 life-size transparent figures, depicting the invisibility of the disease – each one representing **a woman who dies every day** in the UK. The exhibition is part of a drive to raise awareness of the issues and struggles faced by women living with metastatic breast cancer and the urgent need for better care and research.

Each 'Darker Pink' figure features a QR code that, when scanned, plays a video from a real-life woman living with secondary breast cancer. Filmed in 2021, many of these women have since died, themselves becoming a statistic they spoke about whilst also campaigning for change.



The exhibition was placed in public spaces such as libraries, community centres and retail spaces across England and Scotland during our first year. With the sponsorship of Debbie Abrahams MP for Oldham East and Saddleworth, in March 2023 the Dark Pink exhibition was displayed in the Houses of Parliament (see image on front over). Patient advocates were available daily to speak to MPs and members of the House of Lords to explain to decision makers the issues that patients living with MBC face. We intend in the coming year to display the Darker Pink figures in Wales, along with locations in Northern Ireland, because we are committed to supporting all patients across the UK.



TRUE CRIMES

In Breast Cancer Awareness month 2022, we created a TV advert to complement the Darker Pink exhibition which was still touring the UK. Created and produced by Break Creative Partners, with support and assistance from Millk Media in Manchester, the hard-hitting 30 second video was originally scripted and planned to be released across social media channels, but a partnership with media company Guerillascope, saw the advert being shown on mainstream TV across the UK on the 13th October 2022.

Voiced by **Maxine Peake**, it was seen on over 40 spots across 10 channels including ITV, Channel 5 and MTV, reaching an actual total audience of over 2 million. Programmes included Gok Wan, Jamie Oliver, Jeremy Vine, The Great British Bake Off, and prime spots in Emmerdale who were running a MBC story at the time. This elevated

our campaign to a large of people with a hard hitting message in keeping with the #DarkerPink messages. Both the Darker Pink Exhibition and the True Crimes advert provide education about metastatic breast cancer for the public benefit. They complement each other, with the Darker Pink exhibition providing in-depth information about metastatic breast cancer, and True Crimes providing short form information to millions of people as a TV advert and a social media clip.



All of our campaigns were combined with dissemination of the ABCD Red Flag Infographics for ductal and lobular breast cancer. These infographics highlight the signs and symptoms of metastatic breast cancer and are signposted by NHS England to educate patients and the public.

Watch the True Crimes TV advert with Maxine Peak






It's not fun knowing that we feel invisible and that no one is listening to us.

Jo Taylor

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that so many of us are unaware of the red flags symptoms.

Mary Huckle

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that it's a struggle to access any ongoing NHS mental support.

Laura Ashurst

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that there doesn't seem to be a test to show who is or potentially who isn't going to be cured.

Kirstin Spencer

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that I'm planning my funeral. It's not something that someone at 39 years old should be doing.

Carole Pollard

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that I'm less likely to access clinical trials because I take other medication.

Madeline Meynell

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that I had to self fund treatments as there was nothing else approved on the NHS available to me.

Phillipa Hetherington

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**




It's not fun knowing that we don't even have clinical trials based on black women's experiences.

Leila Asoko

Metastatic Breast Cancer

#DarkerPink

THE DARKER SIDE OF **Pink**

RESEARCH AND ACCESS TO DRUGS



METUPUK Aims and Objectives:

- Work with life science companies to increase the number of MBC trials in line with the MBC number of patients, recognising the real potential to extend and save their lives.
- Work to make breast cancer trials more accessible to patients with MBC.
- Submit evidence to the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) to speed up the drug approval process for new drug treatments for MBC.
- Maximise technological advances to improve collation and analysis of data and statistics for MBC.
- Encourage decision makers to use information to better inform treatment decisions.

IMPROVING ACCESS TO DRUGS

Drug access is one of the key objectives of METUPUK because new drugs are needed to increase survival outcomes for patients with MBC. To achieve this we work as stakeholders with NICE and the SMC who are responsible for ensuring that drugs and medical devices are value for money for the NHS.

We bring the patient voice into the drug approvals process. All our written submissions are in collaboration with patients who have the subtype of metastatic breast cancer being reviewed in relation to the proposed drug. We also send patient advocates to speak directly to the committees. The committees are dominated by health economists, scientists and drug companies, and so it is important for these decision-makers to hear from the patients who will benefit from the technology being appraised.

A number of drugs for MBC were approved during our first financial year. METUPUK was a stakeholder participating in the following drug approvals:

- **Trodelvy (NICE and SMC)**
- **Pembrolizumab plus chemo (NICE and SMC)**
- **Tucatinib combination (NICE and SMC)**
- **Enhertu third line (NICE and SMC)**
- **Piqray plus Fulvestrant (NICE)**

All of these campaigns bring vital additional drug options to women and men with MBC in the UK. A campaign we would particularly like to highlight is the approval of **Trodelvy (sacituzumab govitecan)**, an antibody drug conjugate licensed to treat unresectable or metastatic triple negative breast cancer. Trodelvy was granted accelerated approval by the United States and was subsequently licenced in the UK under Project Orbis. Project Orbis was designed to deliver faster access to innovative cancer treatments, but this did not include the health technology appraisal which could take up to a year.

METUPUK patient advocate Dr Philippa Hetherington had triple negative metastatic breast cancer and understood that patients did not have that long to wait. Philippa started the #TrodelvyNow campaign to get Gilead, the manufacturer of Trodelvy, to introduce a named basis pre-reimbursement scheme so that patients could start on the drug before NICE/SMC approval was completed. Much of Philippa's advocacy was done while paralysed from a spinal cord compression and having to deal with a very different new normal. .

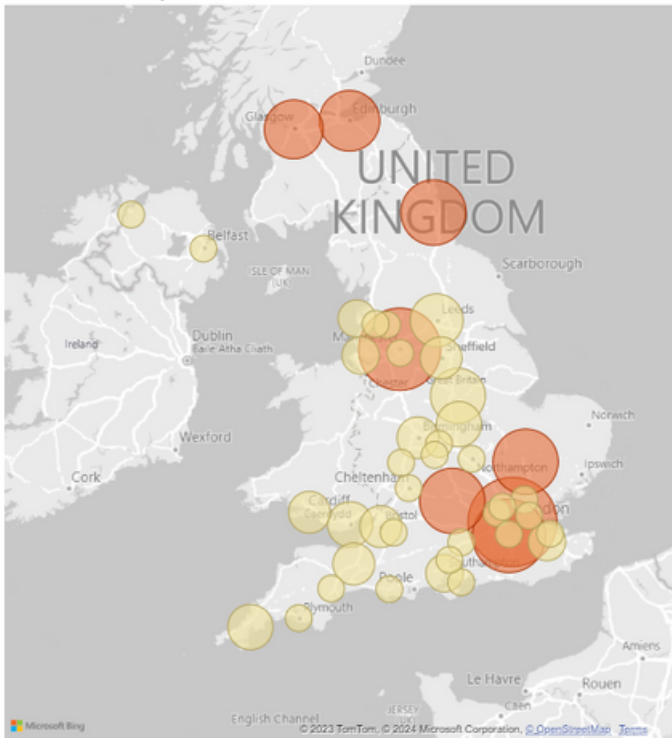
Most of the drugs accepted for use on the NHS this year were made available by both NICE and the SMC. An exception to this was the combination Piqray plus Fulvestrant which was not accepted by the SMC and therefore is not available to MBC patients in Scotland treated within the NHS. This discrepancy shows that unequal access to cancer drugs remains within the UK. We intend to open up discussions with the drug company to discuss if resubmission to the SMC is possible, as part of next year's planned work.

CLINICAL TRIALS

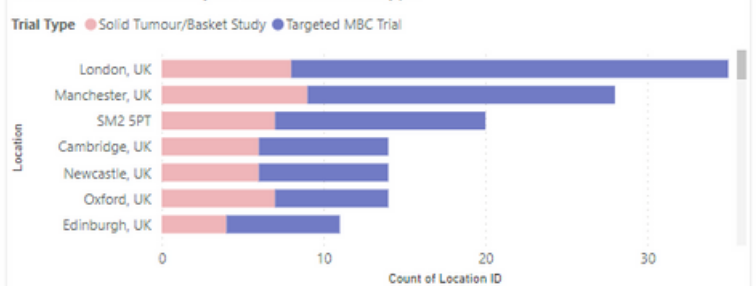
Our work on facilitating access to clinical trials builds on the work started by METUPUK patient advocate Beth Roberts in 2018. She constructed a clinical trials spreadsheet to help patients searching for MBC trials. She recognised that the large clinical trial databases were not fit for purpose, and the large organisations that should have been keeping them up to date were not. Trials were missing, trials that had stopped recruiting were being advertised as still open, trials available for MBC patients were not tagged so did not appear in the correct searches.

Beth died in 2020, and now one of our volunteers, Kat Southwell, has taken this role on. With an IT background, she is developing the trial listing as an interactive dashboard, to be further developed in the next financial year. We will also be collaborating with other third sector MBC organisations such as Make 2nds Count to produce the most up to date information for patients to use, wherever they live in the UK.

Count of Trial ID by Location



Count of Location ID by Location and Trial Type



Trial Name

- A first in human dose escalation and edxpansion study with the antibody drug conjugate BYON3521
- A Safety, Pharmacokinetic and Clinical Activity Study of NUC-7738 in Patients With Advanced Solid Tumours and Lymphoma
- A Study Evaluating the Safety, Pharmacokinetics and Early Efficacy of AVA6000 in Solid Tumours
- A Study of NX-1607 in Adults With Advanced Malignancies
- A Study of Runimotamab in Participants With Locally Advanced or Metastatic HER2-Expressing Cancers
- A Study of SGN-B6A in Advanced Solid Tumors
- A Study of SGN-B7H4V in Advanced Solid Tumors
- A Study of SGN-PDL1V in Advanced Solid Tumors
- A Study to Evaluate the Safety, Tolerability, and Efficacy of MORAb-202 (Herein Referred to as Farletuzumab Ecteribulin), a Folate Receptor Alpha (FRα)-Targeting Antibody-drug Conjugate (ADC) in Participants With Selected Tumor Types
- A trial of CCS1477 for prostate cancer and other solid tumours
- A trial of HMBD-001 for solid cancers that have spread
- Anti-tumor Effect of Ixabepilone in Metastatic Breast Cancer (mBC) Selected by the Ixabepilone DRP.
- Ascending Doses of Ceralasertib in Combination With Chemotherapy and/or Novel Anti Cancer Agents

PATIENT TREATMENT AND CARE

METUPUK campaigns to ensure that patients have access to the best treatment, so that patients can live longer and better. Our work with the drug regulatory bodies NICE and the SMC is an example of how we campaign for the most up to date treatments.

We also campaign for better access to radiotherapy and surgery for patients with MBC. For example, Philippa Hetherington gave evidence to the Parliamentary Health and Social Care Committee in October 2021 about the challenges faced by NHS patients accessing the latest drugs and radiotherapy, and what role science and innovation can play in helping us to bridge the gap in survival rates between the UK and countries such as Australia and Denmark. Philippa had been denied stereotactic radiotherapy for her brain metastases and so had paid out of her own pocket for treatment. Her testimony demonstrated firsthand to legislators the fact that NHS patients do not have access to the most innovative treatments.

An ongoing campaign has been for the provision of Clinical Nurse Specialists (CNS) dedicated to metastatic breast cancer.

This campaign has particular traction in Wales, where patient advocate Tassia Haines has taken it all the way to the Senedd. During and prior to 2022, there was just one MBC CNS for the whole of Wales. Tassia's work has increased the number of CNS posts, but still not enough to cover every patient in Wales. Lack of dedicated CNS provision for patients with metastatic breast



cancer is not just a problem in Wales. There is still much to be done to ensure that every patient has a dedicated nurse to support them at every stage of their illness.

We also have an ongoing social media campaign about living well with metastatic breast cancer. Using the searchable hashtag #BusyLivingWithMets we highlight achievements made by people living with the disease, and use our social media channels to encourage living well. We do not endorse any “wellbeing” activities that are not evidence-based.

Our Chair Jo Taylor is passionate about the benefits exercise and fitness can bring to physical and mental health in cancer, and so are many of our volunteers.

We also recognise the impact that metastatic breast cancer has on friends and family. We have a Friends and Family Facebook group which is moderated by Andy Figgins, who lost his wife Elaine to metastatic breast cancer. The group provides peer support in a safe environment. We do not provide a group for patients with metastatic breast cancer because we do not wish to replicate what is already provided by other organisations. We do signpost patients to groups run by other registered charities.



OUR FINANCES

Financial Review

The Charity was registered on 9th November 2021, with a first financial year end of 5th April 2023. The Charity's income for this period exceeded expenditure by £62k, leaving the Charity in a stable position at the end of the financial year.

Expenditure summary 2021-2023

The Charity's funds have been used effectively and have been spent in line with our objectives. The largest item of expenditure was for attendance at events to further awareness of, and to provide education about, Metastatic Breast Cancer.

Income summary 2021-2023

For the financial period, the Charity's main source of income was fundraising, comprising 85% of the total funding. The remaining 15% was from direct donations to the Charity. Income came from individuals and corporates as well as income from Charity-led fundraising activities.

Charity Reserves Policy

METUPUK holds a minimum of 12 months' running costs in reserve from unrestricted funds. These running costs include IT/telephone costs including Microsoft accounts, website hosting and support, virtual assistant fees and the cost of running ongoing campaigns such as the Darker Pink exhibition. We also need to set aside provision for professional fees such as accountancy and legal advice should the charity be closed. The funding stream of METUPUK relies mainly on donations via funding platforms, which varies month to month. Any funding via grants is generally restricted so cannot form part of the reserves policy.

Our running costs vary according to the number of active volunteers who require IT access and the cost of our campaigns. The reserve set for this year is £25,000, and this figure will be reviewed by the Trustees on an annual basis.

STATEMENT OF FINANCIAL ACTIVITIES

METUPUK	
Charity no: 1196494	
Income	
Fundraising	£73,044.38
Donations	£13,823.83
Other	£15.00
	£86,883.21
Charitable Activities Costs	
MBC Awareness / Education Events	£22,339.35
Education/ Communications	£600.05
Other costs	£660.32
	£23,599.72
Governance Costs	
IT/Website/SM/Telecoms	£770.20
Insurance	£179.32
Legal & Governance Costs	£181.80
	£1,131.32
Incoming	£86,883.21
Outgoing	£24,731.04
Closing Balance	£62,152.17

